

Reaching Out: growing our understanding of the researched



Bridging Change

A report on a series of workshops hosted by Bridging Change on 28th November and 2nd December 2022.

Written on behalf of the Reaching Out Project commissioned by the National Institute for Health and Care Research (NIHR)

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Acknowledgments

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Introduction

In November and December 2022, Bridging Change conducted two separate in person workshops in Brighton and Hove, one for organisations who work with racialised communities and another with people who identify as Black Asian and minoritised ethnic. The workshops were intended to improve understanding of the experience of people who identify as Black Asian and minoritised ethnic people in Brighton and Hove. Many of the participants worked to support minoritised ethnic people. All participants were remunerated for their participation.

This project is building on the previous report, [Reaching Out: building relationships to increase research impact \(Biswas Sasidharan and Hickey 2021\)](#). The intention is to capture a snapshot of a small cohort of Black Asian and minoritised ethnic leaders and individuals in Brighton and Hove and their experience of health and social care, their experience with health researchers, challenges, barriers, benefits and outcomes for ethnically diverse people and finally the benefits of working in partnership with researchers.

The workshops

The workshops began with a 20 minute presentation of the role of the ARC and the NIHR and the significance of health, public health and social care research. Beth Harrison, Public and Community Involvement and Engagement Coordinator who introduced the work of the ARC and NIHR. Dr Anusree Biswas Sasidharan, a spoke about the previous Reaching Out Project. The second part of the session was an hour and 100 minute facilitated discussion facilitated by the directors of Bridging Change (Dr Anusree Biswas Sasidharan and Nora Mzaoui) with participants. The participants considered specific in the workshops:

- What is your experience of health research? Have you experienced (good or bad) research as an organisation or individual?
- How would you want health researchers to engage with you as an individual and as an organisation? What will enable you to engage?



- What health and social issues are impacting ethnically diverse people (children, young people and adults)? What would you like health research to look at?
- What are the challenges and barriers of working in partnership with researchers?
- What might be the benefits and outcomes of working together in partnership with researchers?
- Health and social care research we would like to see . . .

Experience of health and social care

The workshops identified a broad range of experience of health and social care. Some of the participants that they and/or some of the people they supported found that acronyms made it difficult to understand medical literature and the way the clinical staff spoke to patients, making information less accessible. This was also the case with researchers who were not always mindful that they were not medical people. For those who did not have English as a first language or were not medically literate, this made the information inaccessible.

Certain health issues, especially around mental health, sexual health and cancer were sensitive and some members said that this needed to be dealt with particular consideration and cultural competence.

Also research that involved digital methods had an exclusionary impact for those who have English as a second language and who experiences **digital exclusion**. Another limitation to the digital experience was the limiting of responses of respondents which might not capture nuance – sometimes capturing “yes/no” responses and not allowing for space to explain, which left some “feeling silenced”.

There needed to be more involving in the framing of questions to ensure that it captures cohorts’ responses better.



There were concerns that clinical staff could patronise patients, particularly where English language was a barrier but also if a person has an accent.

The experience of COVID-19 perhaps highlighted the importance of understanding the lived experience of racialised people. That there was little understanding of local places and often national research informed local experience, even when there were specific experiences or local contexts.

Also some racialised people were reverential to clinical staff and there was a nervousness around challenging misdiagnosis or inappropriate comments, especially from doctors.

Respondents expressed that experiences in health and social care can create a barrier to wanting to be involved with health and social care researchers. It was important that researchers are able to make people feel comfortable. Some had very positive experiences of research, where **interests aligned with theirs**.

It was important that there were follow ups, whether feedback, it often felt that researchers were “single minded in their agenda” and this sometimes meant that questions were not always thought through, which made it difficult for minoritised people to respond. “Equality needs to be ground in” said one respondent. “creating an equal space.”



What is your experience of health research? Have you experienced (good or bad) research as an organisation or individual?

Respondents were not always clear what 'good' looks like particularly online. It sometimes felt like a tick box exercise. Face-to-face was preferred. Whilst the research collection part of the research was regarded as good and positive the lack of feedback was unsatisfactory leaving respondents unhappy with end result, feeling that it was not representative of their views and not communicated back to groups, individuals or the community. Others described that research did not feel inclusive.

Health visitors and midwives are not sensitive to community needs. It would be helpful for the UK to learn from other countries and the way that they work with communities.

People feel if they have an accent that they are not taken seriously, articulate or intelligent.

"Research organisations often steal ideas from grassroots organisations and do not acknowledge us".

How would you want health researchers to engage with you as an individual and as an organisation? What will enable you to engage?

It was important to the respondents to know that their input was "going to make a difference". There was a need to have ongoing relationships, there are problems when there has an issue by issue situation and not a relationship. Respecting experts by experience and ensuring that questions and methods are trauma informed to ensure that they were not triggering.

It was important to have good communication and being specific so the research is relevant to Black Asian and minoritised people. It is important that people are made to feel comfortable. It is important that researchers do not simply provide lip service, but being honest and build up trust. That answers – come back in a timely fashion and actioned – often nothing happened.



Research should enable a space where people free able to express themselves so researchers should prepare to be flexible. There is a rigidness in research which “needs to connect not just to research but to work alongside community work”.

“It is important that the space feels like a safe space. How people speak to you.”

Respondents expressed they understood that implementation could take a long time but it was important that researchers managed expectations – “perhaps give phone updates periodically, If it is postponed, let people know.”

The respondents said that it was important for their work and/or their contribution to be acknowledged through remuneration and expenses. It was important to consider when people were free which may not be in ‘office hours’ as often they were working or had childcare issues. There was an importance of researchers to show a greater level of flexibility that they currently do in fitting into the people they are researching.



What health and social issues are impacting ethnically diverse people (children, young people and adults)? What would you like health research to look at?

“Women’s sexual health.”

“Criminalisation of young people – calling police – work together more – health issues becoming criminalisation – especially mental health.”

“Ways of capturing better multi-agency need.”

“Reducing weight.”

“Additional barriers.”

“Heard referred to the right place.”

“Diabetes – dismissed – blood pressure.”

“GPs dismissive of people’s experience and health issues – not listened to.”

“Medical stuff – being sensitive - engage culturally or empathic ways.”

“Trying to access the right more expensive treatment/prescription.”

“Not much work happening in social care of children.”

“Autism and race for adults – strategic – social care.”

“Different family structures.”

“All services particularly for adult – EDI.”

“Up-to-date.”

“Innovation.”



What are the challenges and barriers of working in partnership with researchers?

Language

Language was a significant area of concern, not necessarily about translations into English, but the over use of acronyms and medical jargon making research inaccessible. The use of idioms were also problematic as people do not necessarily grow up with the same 'turn of phrase' or expressions. The need for plain English was essential. Also to consider, where appropriate, other mediums such as videos and looking at other languages as appropriate.

“Researchers need to understand the relevance of their work for the people they are researching.”

Sensitivities and cultural awareness

There are sensitivities of issues around sexual health such as cervical smears and mammograms which are of course important but there was a recognition in the group that this was not dealt with culturally or sensitively. It was important to raise awareness around these issues and “important to educate but not preach.”

Another area of stigmatisation was mental health which needed to be handled sensitively and culturally appropriately.

“Their lack of knowledge and cultural awareness can mean that people can have a bad experience.”

The important of considering the significant of *izzat* (concept of 'honour') which is observed by more conservative communities. Issues such as these need to be considered by researchers. However, it was equally important to not make assumptions about communities and individuals.



Trust

Being able to trust researchers was a strong theme amongst respondents, it was felt that it was about developing rapport and taking the time to have a conversation. What was strongly felt was a needed to have a more substantial relationship with researchers/research bodies and not one off relationships.

What might be the benefits and outcomes of working together in partnership with researchers?

“Make a real difference and change current thinking.”

“Learning, mutual learning.”

“Learn about communities.”

“Being interactive with communities and co-production.”

“Listening and validating the experiences of black and brown people and getting feedback improvement of service.”

“Being taken seriously.”

“Being able to co-produce properly with researcher.”

“Capturing new voices from different equality group.”

If not done properly it would exacerbated inequalities, so ensure there is good engagement with community groups and individuals.”

“Important to look a recruitment.”

“Researchers giving up privilege and hierarchy.”

“Consider intersectional experience.”



What we would like to see in health and social care research . . .

There was a sense that there was a disconnect between local evidence capturing the “actual experience” of Black Asian and minoritised ethnic people – to “capture the reality”. This reality would include inclusion of more mixed heritage people and the acceptance of alternative models of understanding the physicality and reality of skin colour and how colour of trauma may vary and ensure black and brown skin is better understood and included in models of care.

As well as the importance of recognising the diversity of amongst different ethnic groups so was the family dynamics, the values, voices that contribute, and understanding that there is diversity within ethnic groups. Often many assumptions are made based on “the white experience” and approaches of researches should include more person centred or patient centred approaches. The importance of being culturally informed in the way questions were asked.

There was also recognition that intersectionality identities such as learning disabilities for example needed to be considered. There was also an interest in the group to perhaps consider how to reach the seldom heard such as those with learning disabilities/difficulties who had barriers to communication and looking at ways to reach people who may require advocacy.

Conclusion

Respondents’ were keen to work with researchers on a much more equal basis, some were keen to look to community researchers as a way to help grow knowledge and use community development skills much more in researcher so that it could improve access for researchers but also enable a more accurate understanding of minoritised ethnic people.